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Understanding and Improving Health Education Among First-time Parents of Infants With Sickle Cell Anemia in Alabama: A Mixed Methods Approach

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Summary

With the increase in access to medical information, parents can acquire health information from multiple sources. An understanding of parents' reactions to a newborn infant's diagnosis of sickle cell anemia and how they acquire knowledge can identify parent beliefs and preferences about the process of sickle cell education. This study utilized a sequential exploratory mixed methods design. First, qualitative interviews were conducted with 8 parents of infants with sickle cell anemia to understand the process of health education. Second, quantitative surveys were conducted with 22 other parents to test qualitative findings. Parents of infants with sickle cell anemia expressed a high level of fear at the time of notification of a positive screen. Parents desired an understanding of how to identify acute complications of disease and how sickle cell will alter their child's life. Parents actively sought information at the time they were told their child had sickle cell disease. Sickle cell education should begin at time of notification of positive newborn screening results and address identified parent concerns. Health care providers should build trust with parents and provide them with immediate access to educational materials. Hematologists should work with primary care providers to develop complementary educational programs and resources.

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Keywords

parenting education; newborn screening; sickle cell anemia; qualitative research; quantitative research methodology

It is vital for parents of an infant with newly detected sickle cell disease to quickly acquire accurate health information about their child's condition.[1] When parents first learn their infant has sickle cell disease, they may be overcome with anxiety; accurate information can help allay their concerns as well as motivate them to take actions to improve their child's health. In particular for sickle cell anemia, parents need to begin to learn about the importance of adhering to recommended prophylaxis, including penicillin, vaccinations, signs, and symptoms of acute exacerbations that require immediate medical attention, and options for therapies such as hydroxyurea.[2–5]

People typically obtain health information from several sources including health care professionals, peers, and self-directed education (eg, Internet, books). Internet-based self-education has been increasing and is often used by patients or parents before receiving education from their physicians or to obtain information that either challenges or supplements advice from health care professionals.[6–8] For parents of infants diagnosed with sickle cell disease, a number of accurate sources of information are available online including http://www.nhlbi.nih.gov/health/health-topics/topics/sca/ or http://www.nhlbi.nih.gov/. and http://www.cdc.gov/ncbddd/sicklecell. Other informational resources, including ACT sheets from the American College of Medical Genetics and Genomics, are targeted to primary care providers responsible for reporting newborn screening results to parents (http://www.ncbi.nlm.nih.gov/books/NBK55827/).

No research that we are aware of addresses the reactions and beliefs of parents toward the process of sickle cell disease education following newborn screening and diagnosis of sickle cell disease, although a number of studies have examined parent reactions to being told their child is a carrier or has sickle cell trait.[9–12] It is important to collect this information from parents to develop more appropriate parentcentered health education materials. It is recommended that health care practices should incorporate the parent/patient perspective when designing health education materials.[13–15]

In the state of Alabama, parents of infants that screen positive for sickle cell disease (newborn screening hemoglobin identified as FS, FSC, FSA, or FSD) are notified by their child's pediatrician of the tentative diagnosis and during a primary care visit are provided basic information about the disorder. They are also typically referred by the pediatrician to the University of Alabama at Birmingham (UAB) sickle cell clinic. For those who choose to attend, the first clinic visit is typically at 2 to 3 months of age for confirmation of the diagnosis and management of the disorder. The state screening program also provides the names of all newly detected infants to the UAB sickle cell clinic and community-based organizations to help ensure that infants identified with sickle cell disease are started on penicillin and attend their referral appointment by 3 months of age.[16]

During their first UAB sickle cell clinic visit, parents of newly diagnosed infants with sickle cell anemia (newborn screening result of FS confirmed as sickle cell anemia) watched the first of 11 videos developed by the institution as part of the BABYSTEP education program (https://www.childrensal.org/BABYSTEP), followed by discussion about sickle cell disease during their infant's examination by a physician/practitioner. The initial video education session seen by all parents who participated in this study includes the following topics: (1) general overview of sickle cell disease including types of sickle cell disease (such as sickle cell anemia); (2) infection in sickle cell disease including how to measure temperature; (3) need for penicillin prophylaxis and vaccinations; and (4) common problems experienced by infants including dactylitis, splenomegaly, and pneumonia.

This project was designed as part of a course on qualitative research methods to improve understanding of how parents acquire health information about the disease around the time their child is diagnosed. Diagnosis of sickle cell disease is a process that extends from the initial reporting of newborn screening results to final confirmation by a specialist. Parents of a first-diagnosed infant with sickle cell anemia seen at the sickle cell clinic at UAB were the target population. Specific goals were to identify what topics are pertinent to parents at their initial sickle cell clinic visits, how and when they would like to learn about the disease, and what motivates them to seek health information.[17] In addition, the project sought to evaluate the perceived usefulness of the education materials used at the UAB clinic.

Materials and Methods

Sequential exploratory mixed methods research allows an in-depth qualitative exploration of a phenomenon with a few individuals followed by a quantitative phase conducted in a larger population to confirm or refute the qualitative findings.[17,18] The qualitative goals for this study were to use in-depth interviews with first-time parents of infants with sickle cell anemia, that is, infants without an older sibling previously diagnosed with sickle cell anemia, to identify categories and themes about the process of parent health education. The quantitative goals focused on confirming these themes about health information through surveying a larger population of parents. Mixed methods data integration was performed to allow for generating more valid conclusions and ensuring transferability of findings.

Qualitative Research Methods

Semistructured interviews were conducted over a 6-week period with 8 first-time parents of infants (below 12mo of age) with a newborn screening hemoglobin profile result of FS, who attended the UAB Pediatric Sickle Cell Clinic and were diagnosed with sickle cell anemia (HbSS or HbS/Beta Zero thalassemia) (Appendix I, Supplemental Digital Content 1, http://links.lww.com/JPHO/A74). Parents received a recruitment letter before their first clinic visit that described the voluntary nature of the study and the list of main questions that would be asked if they chose to participate. Participation by parents in the interviews implied consent. The interviews were conducted as part of a graduate-level course on qualitative methods for educational research; at the completion of qualitative data collection, an IRB at UAB retrospectively approved the collection of the qualitative data and prospectively approved the quantitative survey. Semistructured interviews (30 min) were led by 4 different

researchers with training in qualitative research methods using the same interview protocol (Appendix I, Supplemental Digital Content 1, http://links.lww.com/JPHO/A74). No personal health information was collected. The questions addressed the following topics: (1) parents' initial feeling/response to learning about their child's diagnosis; (2) identification of sources parents used to acquire health information about sickle cell anemia; (3) ease of understanding source used for health information; (4) additional information desired about sickle cell anemia; (5) response to learning about sickle cell anemia; and (6) format desired for education. The interviews were conducted before or during one of their first 3 sickle cell clinic visits (at approximate ages of 3, 6, and 9 mo) either during the sickle cell clinic visit or over the phone. Each interview was audio recorded and a rough transcript was generated by the interviewer and reviewed by the interviewer for accuracy.

Four researchers independently developed codes (characterizations of unique quotes) from each of the transcripts, capturing all unique, purposeful quotes from interviewed parents. Codes identified and agreed upon by at least 3 of the researchers were entered into NVivo qualitative data analysis software from QSR International (Burlington, MA).[19] Using the constant comparative approach, the codes were placed into preliminary categories. The data collection and analysis process followed a “zigzag” pattern (first, parent 1 interviewed and transcript analyzed for codes and preliminary categories; then parent 2 interviewed, transcript analyzed for new codes followed by new or revision of categories, etc.). This was continued until no new codes or categories were identified during the last interview, a stopping point known as data saturation.[20] A final codebook included 61 codes (Table 1). The 4 researchers unanimously agreed upon the final categories and themes. Trustworthiness of the qualitative findings was attained through triangulation of methods, thick-rich descriptions, intercoder reliability, and peer review.[18]

Quantitative Research Methods

The survey was designed to specifically test the categories and themes identified by parents during the qualitative research phase. The survey questions included: (1) sources of information used by parents to learn about sickle cell anemia before seeing their hematologist; (2) how/from whom they would like to learn about sickle cell anemia; (3) their emotions upon hearing their child was diagnosed with sickle cell anemia; and (4) their attitudes about the institutional educational video program (Appendix II, Supplemental Digital Content 2, http://links.lww.com/JPHO/A75). Survey questions were pilot tested among another group of parents of children with sickle cell anemia for content and understanding. The quantitative survey was conducted by 1 researcher (J.D.L.) with 22 first-time parents of infants with sickle cell anemia who attended the UAB Pediatric Sickle Cell Clinic and who had not participated in the qualitative interviews during a 4-month period. In the clinic, parents were given an information sheet about the voluntary study and a copy of the survey (Appendix II, Supplemental Digital Content 2, http://links.lww.com/JPHO/A75). Parents who decided to participate in the written survey were asked to complete the survey and return it in a sealed envelope to the researcher. The researcher was present to answer questions from parents as they completed the survey. Completed surveys were analyzed using JMP10 software (SAS Institute Inc., Cary, NC) to identify score distribution and descriptive statistics.

Results

Qualitative Interview Findings

Eight parents (7 females, 1 male) participate in the qualitative interviews. The major themes identified from the qualitative interviews were parental fear of sickle cell anemia and trust in sources of health information. Parents expressed fear of disease in general, of complications of sickle cell anemia, and of having a child with a chronic illness. A general fear of sickle cell anemia was expressed by several parents when asked, “How did you feel when your child was diagnosed with sickle cell anemia.” One parent described her initial reaction to learning the diagnosis as “(I was) devastated, cried, and prayed. I know this is bad but I immediately started wondering how long she would live.” Another participant described her feelings as “terrified, real scared.” The fear of the disease included the economic impact of caring for an infant with sickle cell anemia. “I worry about her and how I will take care of her. I already work a lot and we struggle with paying the bills and how much everything costs these days. I feel sad but also mad.” Even at diagnosis, 1 parent expressed fear about the potential stigma of drug-seeking behavior often attributed to patients with sickle cell disease: “I remember when my auntie went to the ER; they made her out to be a drug seeker. I don't know why I am even thinking about that but I don't want my baby to be treated different.” Another parent was fearful of chronic complications not associated with sickle cell anemia, asking “Will sickle cell cause cancer.” Finally, 1 parent expressed a fear of how her child's disease would alter her personal relationships “as she gets older and goes to school and has friends.”

The fear of sickle cell anemia prompted some parents to seek out health information. One parent stated, “I'm sad and worried and wish I just knew more.” The topic on which parents most frequently sought information was how to care for an infant with sickle cell anemia, specifically on understanding when their child was experiencing an acute complication. “Since she isn't talking yet, I want to know how to tell if she is sick,” “What signs to look for since my child can't tell me when she is feeling bad,” or “What are the restrictions I need to prevent episodes from occurring.” Other parents expressed their concerns about educating others who would be caring for their infant. “What are the signs and symptoms of sickle cell anemia that I need to be looking for? I would like to know what to expect if he goes to daycare, what to tell the teachers.”

The second identified theme was trust in sources for obtaining health information. Most parents reported having sought out information through several sources before their first visit to the sickle cell clinic. Parents most frequently reported having used the Internet, sickle cell pamphlets provided by their primary care physician, and family members as sources of health information. “I don't have time to read and don't like to, but the Google helps when I don't know if she acts the way she should.” Pediatricians were identified as an important source of information, “It's easy (to learn) at the doctor's office, but not so much when you try to find out other ways.” Another parent described the benefit of receiving a sickle cell pamphlet from her pediatrician. “The pamphlets were very good.” Although parents expressed trust in health care professionals providing health information, 1 parent expressed some concern about their pediatrician prescribing penicillin for pneumococcus

prophylaxis. “With the penicillin, I have heard that taking antibiotics for so long can decrease the effectiveness of it for an extended amount of time.” Parents also expressed a high level of trust in information from family members. Parents without family members with sickle cell disease reported difficulty finding parents or patients with sickle cell anemia to engage in education. “I would like to talk to moms about it but I don't know who to talk to” or “It's hard to find people who are living it out.”

Finally, the use of a video education program at our institution was reported by many parents as helpful, improved their comfort level, and had stimulated them to pursue topics they had not previously considered. Parents stated that “I liked the video a lot,” “It will help me better know how to take care of her,” “I found out that his sickle cell isn't the worst case.” One parent who had extensively pursued self-education through the Internet felt the video did not address their concerns, “(the video) pretty much regurgitated what I learned online but the video is somewhat outdated. It would help if it came from the perspective of 2011.”

Quantitative Survey Findings

Parents surveyed confirmed several of the fears about sickle cell anemia identified during the qualitative interviews. The concern identified by most parents was whether their child would “live a long life” (83%), whereas the least identified concern by parents was whether “will my child be treated differently by friends” (8%). The motivation to learn identified by most parents included both understanding “when my child is sick” (75%) and knowing “how other people will know how to take care of my child when I'm not there” (75%).

The quantitative results from the surveys confirmed the qualitative findings that parents actively seek health education before their first sickle cell visit. Eighteen of 22 (82%) parents surveyed obtained health information about sickle cell anemia before their first sickle cell disease clinic visit and 21 of 22 parents (95%) recommended that information be sent to them at time of first diagnosis following newborn screening rather than waiting until their child's first sickle cell clinic visit, typically at age 2 months. The 1 participant who did not want to receive educational materials stated that she would rather learn from her doctors than independently. Parents used several sources to obtain health information before their first sickle cell clinic visit with the most likely sources being their pediatrician or the Internet (Table 2). This is consistent with parents' prior qualitative statements: “My pediatrician gave me a pamphlet that was very helpful” or “Google helps when I don't know if she acts the way she should.”

Parents suggested that the most important educational information that doctors could provide parents would be a list of approved Internet sites (63% of parents responded as very important) or an educational pamphlet (55% of parents responded as very important). According to parents, the least desirable means to acquire health information is from peers (64% responded peer education was of minimal importance or of no importance). Finally, 90% of parents surveyed felt the video education was “Very helpful” without a clear distinction of the setting in which the video should be used (home, clinic, or both) and whether this could be provided at diagnosis.

Discussion

Patient-centered research can identify parents' beliefs and desires for education that can be incorporated into an institutional sickle cell education program. Parents expressed several fears related to their child's screening notification of sickle cell anemia, which prompted an immediate desire to acquire health information at time of diagnosis. Parents who were not provided with educational materials at the time of diagnosis demonstrated a tendency to seek out their own sources of information. The topics most important to parents of a newly diagnosed infant with sickle cell anemia in our sample include: (1) how to identify acute complications of disease in an infant; (2) how to care for an infant with sickle cell anemia; and (3) how sickle cell anemia will alter their child's life. Our interpretation of the expectations and desires of these parents is that, education about sickle cell anemia should begin at the time of presumptive diagnosis (often by the primary care provider) rather than deferring this education to the sickle cell provider (around 2 to 3mo of age).

On the basis of this research, we identified 2 approaches that could be used to enhance our parents' educational experience. First, sickle cell centers often have educational material about sickle cell disease on their institutional Web sites and several parents identified the Internet as a source of seeking health information. Thus, when sickle cell centers contact parents to confirm their first appointment date, a list of trusted Web sites, including an institution's Web site, should be provided so that parents are directed to sites that have been approved by their treating hematologist. Second, sickle cell centers should work with pediatricians who will see patients before a parent's first trip to a pediatric hematologist to begin education about both the disease and available clinic-based and community resources for patients with sickle cell disease. The themes identified in this research as vital to parents can be addressed during initial visits to their pediatrician including education on identifying acute complications (fever, dactylitis) that require urgent medical care, initiation and rationale for pneumococcal prophylaxis (penicillin/vaccinations), and improved outcomes for patients (increase in survival).[2,5,21–23] As possible mistrust about prophylaxis against pneumococcus was mentioned by a parent, we believe that pediatricians and hematologists should be consistent and repeated in their education about the importance of vaccination and penicillin prophylaxis.

This is the first paper to the best of our knowledge to identify motivators to acquisition of health information among parents of infants with sickle cell disease. Previous literature has explored the responses of pediatricians and parents of infants identified with sickle cell trait following a positive newborn screen.[9,10,12,24,25] Two concerns noted in the literature for sickle cell trait relate to the primary care provider. First, despite near-unanimous support for newborn screening, there are deficiencies in pediatricians' knowledge about the clinical significance of sickle cell trait, which could lead to inaccurate education for parents. Second, unidentified barriers exist for pediatricians who display a reluctance to immediately review trait status with their patients. One survey of pediatricians reported that only 3% of pediatricians felt they needed more information about sickle cell trait, but 73% of these pediatricians responded that they were waiting until their next appointment to discuss the positive sickle cell trait newborn screen result.[26] The barriers identified for primary care providers in the sickle cell trait literature (need for increased education and delay in

discussion with families) may exist in the sickle cell disease community as well and highlight the need for pediatric hematologists to work with pediatricians to provide them with complementary sickle cell educational materials and to start parent education earlier.

In the present study, the dominant emotional response expressed by parents of infants with sickle cell anemia was fear. The immediate response to a positive screen for sickle cell trait may include surprise and anger, particularly among parents of infants who were unaware or poorly educated about the condition before being tested.[27] In contrast, parents of infants that screened positive for other chronic conditions such as cystic fibrosis or hearing loss have been reported to express emotions of guilt, anger, or depression.[9,12,27–29]

The use of mixed methods research can maximize the benefits of each component of research (qualitative and quantitative) while minimizing their limitations. Limitations for this study include potential selection bias resulting from restriction to parents seen at 1 treatment center, although the majority of newborns in Alabama are seen at this center. Recall bias might be an issue as some parents were not seen until 6 or 9 months after their child was born. Further, exposure to the BABYSTEPS video at the clinic might have influenced their retrospective perceptions of need for information. Researcher bias may have influenced the data analyses. Individual researcher bias was minimized in the qualitative study phase as the research questions were developed and analyzed by 4 professionals during a graduate-level course supervised by an expert in qualitative research.

Another potential limitation is a small sample size for the quantitative component. To increase the sample size, researchers could significantly increase the time for surveys (wait for additional infants without siblings with sickle cell anemia to be born) or expand the survey to other institutions (could be considered a threat to reliability for mixed methods research as other institutions were not included in the qualitative component). Although the overall number of parents surveyed was small, merging of data identified concordance for some of the main themes/categories developed in the qualitative analysis. In particular, common themes identified during qualitative research, such as parents seek health education at the time of diagnosis and parents are fearful of the disease, were also prevalent beliefs among parents who were surveyed; 95% surveyed parents would like health education before their first visit and 75% want to learn when their child was acutely ill. The sample size for the qualitative component seems to be adequate as data saturation was achieved (no new information was gained during coding of the final interviews).

Despite these potential limitations, the mixed methods research yielded valuable insights into how some parents react to the diagnosis of sickle cell anemia communicated through newborn screening results. Patient-centered research is vital for providers to maximize their understanding of patient/parent beliefs and values when delivering health care and health education. Parents of infants with sickle cell anemia may express fear as an initial emotion and display a strong desire for immediate education. A strong motivator for pursuing this information is a fear by parents that they will not be able to identify an acute complication of sickle cell disease in their infant. If educational materials are not provided by health care professionals at the time of diagnosis, some parents will seek their own sources of education.

After reviewing the results of this study, we suggest providing educational materials at the time of notification of a positive screening result for sickle cell disease to address the fears expressed by first-time parents of infants with sickle cell anemia. Health care providers who communicate newborn screening results should consider options for providing parents with immediate access to educational materials that includes an overview of sickle cell disease with specific information about acute complications of sickle cell disease in infants. Pediatric hematologists can work with pediatricians and local community-based organizations to develop trustworthy educational materials for them to distribute to parents. This health education could incorporate both traditional educational hand-outs and Internet-based education. In addition, pediatric hematologists should provide complementary education during the first sickle cell clinic visit. Future patient-centered research might explore how to develop/enhance an institutional sickle cell education Internet site that is trustworthy to parents and alleviates the fears expressed by parents. Finally, sickle cell centers could develop a network of trusted providers to educate parents of infants with sickle cell anemia and other types of sickle cell disease before subspecialty referral.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Codebook

Theme	Category (Subcategory)	In Vivo Code
Fears about SCD that motivates health education	Fear of disease at time of diagnosis	I was upset and scared
		Devastated, cried, and prayed
		I was hoping they would come in and say they had the wrong folder
		Sad but also mad about it. I wondered too what I could have done different, but was told it didn't have anything to do with what I ate, drank, or drugs
		I'm sad and worried, just wish I knew more
		I got to be honest, it was hard, it hurt
		I was actually upset because the whole time my child was in the hospital and all the doctors were saying he was fine
		I was confused almost like a bad dream like a train in my ear couldn't hear what the doctor was saying but he kept talking
	Fear of disease severity	Since she isn't talking yet I want to know how to tell if she is sick
	Recognizing acute events	I would like to know how sickle cell can hurt my child
	Life-threatening disease	How long they think my baby will live and what I should be thinking about as far as food goes because she will start eating soon
	Living with a chronic disease	What do I need to look for
		With all of the germs and viruses spreading crazy, I want to know what to look for now and as she gets older
		Things like signs to look for
		I want to make sure I do the medicine right and see the signs right if she is feeling sick from the medicine or just a cold or something
		What signs to look for since my child can't tell me when she is feeling bad
		I would like to know the effects of SCA, how it would affect my child today
		What are the signs and symptoms of sickle cell anemia that I need to be looking for in my child
		What are the restrictions I need to prevent episodes from occurring
		I know this is bad but I immediately started wondering how long she would live you know I heard years ago chances for living past 25 didn't look good
		Will SCA cause cancer
	Fear of social stigmata	I don't want her to be treated different because she has this disease
		I want to know what kind of effect this is going to have on baby's life as she gets older and goes to school and has friends
		Doctors made her (aunt) out to be a drug seeker and it upset my mother really bad. Sorry don't know why I am even thinking about that but I don't want my baby to be treated different
	Practical concerns	I would like to know what to expect if he goes to daycare. What do I need to tell the daycare teachers about sickle cell as well as if children in the daycare are sick, what we need to do
		I am worried about her and how I will be able to take care of her of diagnosis. I already work a lot and we struggle you know, with paying the bills and how much everything cost these days
Parents seek health education	Internet	I have also looked on Internet because one of our nurses gave me a Web site to look up
		I looked on Google

Theme	Category (Subcategory)	In Vivo Code
		We looked on the Internet and found the information we were looking for
		We don't have Internet right now so I can't look up like before
		I don't have time to read and don't like to, but the Google helps when I don't know if she acts the way she should
	Peer education	Talking about it to family and friends (but not to other parents with sickle cell children)
		She has been able to answer most of my question (sister has disease). I saw her go through this as a kid so I know what it's like
		I talked to one of my sister's girlfriends who has sickle cell anemia
		I discussed with cousin who has the disease
		It's hard to find people who are living it out
		It's hard to find people that have the same situation
		I would like to talk to more moms about it but I don't know who to talk to
	Books	I have been to library a couple of times and checked out some books. Some of them were written for doctors I think because I didn't understand them too well, but I did find one that answered some of my questions, but it was like more adult-like than rather than babies
	Pamphlets	It's been very easy to learn (from pamphlets)
		Getting information from PMD. Pamphlets about sickle cell disease were very good
	No source	It's been difficult to learn about it
Trust of educational sources	Medical staff	It's easy (to learn) at the doctor's office, but not so much when you try to find out other ways
		The doctors could talk to me more or the nurses or give me something that they think would help us better understand like a checklist or something I can take with me
		I want to be able to ask the doctors and nurses questions and for them to tell me where to go to find answers to the questions that I have
	Family members	I had an auntie who I had known about that had it so I was familiar with the disease from seeing her with it, but I didn't realize the difficulties that I later heard she hid from us
		I have talked to my sister, she has it
	Peers	I also asked people I knew with it (but I did not learn much from them)
Video education	Benefits	I found out that his sickle cell isn't the worst case
		I was put at ease by the classes
		Because I forget sometimes when the doctors are talking a lot what I need to remember
		I liked the video a lot. I like how they broke it down
		I liked the part about medicines and how to give it
		It was real good. I really liked the video
		The part on how to give your child penicillin was very helpful
		It was very informative, I will give them that it did go over the basics and cover the basics
		I liked the video a lot. It will help me better know how to take care of her
		I am very comfortable with getting information about it (through video)
	Negatives	It pretty much regurgitated what I learned online but the video is somewhat outdated. It would help if it came from the perspective of 2011. It would help if it included all the advancements and all the new

Theme	Category (Subcategory)	In Vivo Code
		drugs and where it is going today. You know, give some hope, give an idea of where the science is heading. That would help
		One thing the video did not go over was the pain as far as what to look for in my child. You know like if my child is having pain in his bones, or I'm hurting somewhere and the oxygen is not getting to a particular tissue, you know
	Setting	I like a combination of time with the doctor and the video. I think the video was informative

Table 2

Linking Survey Results for Sources of Acquiring Health Information With Qualitative Codes From Semistructured Interviews

	n(%)		
Sources	**Survey Response Very Helpful/Helpful**	**Survey Response Minimally Helpful/Did Not Use**	**Qualitative Codes From Interviews**
Pediatrician	13 (72)	5 (28)	“My pediatrician gave me a pamphlet that was very helpful”
Internet	13 (72)	5 (28)	“I looked at the Internet because a nurse gave me a Web site” (the video education) “pretty much regurgitated what I had already learned online”
Family members	11 (61)	7 (39)	“I talked with my cousin who has the disease”
Books	8 (44)	10 (56)	“I have been to the library a couple of times to check out some books. Some of them were written for doctors because I didn't understand them too well, but I did find one that answered some of my questions”
Friends	6 (33)	12 (67)	“I have talked about it to family and friends”
Sickle Cell Foundation	4 (22)	14 (78)	“The foundation helped my sister so I went there”